DESIGNING A PEDIATRIC EPILEPSY POPULATION MANAGEMENT DASHBOARD

A Thesis

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of Medical Sciences

in Partial Fulfillment of the Requirements for the Degree of

Master of Science in Health Informatics

by

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ABSTRACT

Rationale In the US, 460,000 children have epilepsy. Many respond well to treatment in the outpatient setting. It is unclear what the core concepts are that should be displayed for a population of children with epilepsy. The present research aims to advance visualizations for pediatric epilepsy population management by interviewing and surveying physicians to uncover these core concepts.

Methods This is a qualitative methods research project. A convenience sample of pediatric neurology experts participated in a 20-minute interview designed to identify clinical concepts relevant to managing a population of children with epilepsy. We performed thematic analysis on the transcripts to generate a preliminary list of core concepts for display. A survey was distributed to measure expert agreement on clinical concept ranking and to assess data accessibility in the electronic medical record. In parallel, we developed prototype clinical dashboards to explore relevant data visualizations.

Results The interview phase of the research concluded after 14 interviews. The clinical concepts extracted from interview analysis spanned 9 core topics, with 33 sub-categories. The prototypes illustrate the potential to display data related to geography, visit history, medications, imaging, and epilepsy diagnosis. Survey results showed that the top three clinical concepts were epilepsy characteristics, medication data, and testing results. Participants responded that the most difficult to access data points were community factors and family communication barriers.

Conclusions There is a core set of clinical concepts relevant to identifying children with epilepsy with increased risk of emergency department visits. Of these clinical

concepts, many are stored in the electronic health record, and could be readily extracted for use in clinical dashboards. Certain aspects, like parent demographic data and social support factors, are relevant in treating a population of pediatric epilepsy patients but are not readily available in patient data.

BIOGRAPHICAL SKETCH

Torrey Hill is a candidate for a Master of Science in Health Informatics degree in the Department of Healthcare Policy and Research at the Weill Cornell Graduate School of Medical Sciences. He received his Bachelor of Science from Kennesaw State University in 2015 in Psychology and Statistics.

DEDICATION

I gratefully dedicate this work to those who have inspired and encouraged my academic pursuits through the many years. I thank my parents and grandparents for their support and compassion. A special feeling of gratitude to Maredith and the Sapp family for their kindness and understanding.

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INTRODUCTION

Background

Epilepsy is a common chronic neurological condition characterized by unprovoked seizures. The official definition requires at least two unprovoked seizures occurring more than 24 hours apart, or one unprovoked seizure and a 60% probability of further seizures over the next ten years, or diagnosis of an epilepsy syndrome. (1) The causes of epilepsy vary widely and may include acquired brain injuries, structural brain lesions, or genetic predisposition. In the United States, epilepsy affects approximately 1.8% of adults and 1% of children, or roughly 4.3 million adults and 750,000 children.(2,3) Within the population of 5.1 million previously diagnosed epilepsy patients, approximately 2.4 million adults and 460,000 children have active epilepsy.(3) The estimated indirect and direct costs of epilepsy in the United States is $15.5 billion per year. (3,4)

Epilepsy is an ambulatory care sensitive condition. (5) Gaps in outpatient management can lead to increases in health services utilization, particularly the emergency department.(5) For pediatric patients with epilepsy, frequent visits to the emergency department is often an indication of a poorly managed seizure and/or poor access to care. (6)

Research in Epilepsy Informatics

As the amount of electronic health record data increases, several investigators have developed innovative visualizations to help clinicians manage complex information. These include techniques to visualize clinical information for individual

patients, as well as to review large numbers of patient records and events.(7) Previous research in epilepsy informatics has introduced new methods to visualize data specific to people with this disease. For example, Hafeez et al., developed a patient-level timeline view based on clinical data extracted from an EHR to describe the clinical course of children with status epilepticus, a neurologic emergency. The visualization of this data provides a quick view of important clinical data to guide in-hospital management of this vulnerable population.(8) Loddenkemper et al. produced a visual overview of a population of children with epilepsy. In addition to visualizing patient-level and population-level information associated with the patient cohort, their software (EpViz CER) can incorporate modules for predictive modelling and other analytics.(9)

Gaps in Current Research

One of the ongoing challenges to the creation of effective display of clinical information to physicians is the design process. In the past, clinical information displays have been designed by computer scientists and engineers, with little physician input. (11,12) For example, Ratwani et al.'s recent analysis of the user-centered design methods of EHR vendors found that only four of eleven vendors had a well-developed user-centered design process. The remaining seven vendors had basic user-centered design processes or had a misconception of user-centered design.(13) As a result of inconsistent user-centered design methodologies within EHR development, physician usability can be a major problem in new workflow implementations within the field.(14) One research team found that 15% of physicians using a specific

implementation of an EMR tool still requested access to outside information that was not available within the designed program.(12)

More recently, however, physician input has grown in importance in the design of data displays. For example, there is a new-found emphasis on "physician-approved" designs in clinical dashboards and EMR implementations.(15,11) One of the core components of physician centered design is to include a robust process to gather physicians' preferences and priorities for the data that they would like to review in a display. In pediatric epilepsy, there is little published guidance to understand these preferences and priorities.

Current Aims

The present research proposal aims to inform the design of clinical dashboards for pediatric epilepsy physicians. Specifically, we aim to answer the following questions: What information do pediatric epilepsy physicians seek out when assessing the treatment of a population of patients? Do pediatric neurologists agree on the top clinical concepts relevant to treating a population of pediatric epilepsy patients? How can population-level clinical concepts be visualized in the pediatric neurology outpatient clinic?

METHODS

Study Design

We performed semi-structured interviews of a national convenience sample of pediatric neurologists in the United States and Canada to determine the core clinical concepts relevant in treating pediatric epilepsy patients. We subsequently fielded a survey to a convenience sample of pediatric neurologists to determine the rank of importance of the clinical concepts gained in the interview portion of the research. In addition to the ranking of clinical importance, we also aimed to assess physician opinion of data accessibility in patient electronic medical records. This information informed the design of a prototype clinical dashboard. This research was approved by the Weill Cornell Medicine Institutional Review Board.

Interview Design and Methodology

The semi-structured interviews consisted of 5 topics: Clinical Role of the Subject, Current Use of Electronic Health Data, Opinions on ED Use for Children with Epilepsy, Two Clinical Concept Scenarios, Current Barriers and Facilitators. At the conclusion of the semi-structured script, the interviewees had the option to ask questions and provide comments. The same researcher interviewed each participant, and adhered to the semi-structured format of the script to maintain consistency in the interview process. Interviews were conducted in-person or by phone. Each interview was recorded and transcribed for analysis.

Analysis: Qualitative Research Methods

We used two qualitative research methods to analyze the transcripts: thematic analysis and descriptive list generation. Thematic analysis is a type of content analysis in which the researchers extract meaning from the interviews independent of any preexisting theory or epistemology.(16) The inherent flexibility of thematic analysis allows for applications across a broad range of fields. Descriptive list generation allows researchers to build categorical structures based on interviews and focus groups. (17)

Our sample size was determined by the concept of thematic saturation, in which the investigator repeats the interview process until no new concepts emerge. Sample sizes of 15-20 subject matter experts is common; though thematic saturation can occur as rapidly as in the first 6 interviews. (18,19) Due to the relative homogeneity of the field within the treatment band of pediatric epilepsy, we expected thematic saturation to occur rapidly.(20)

Analysis of interview transcripts was completed independently by two reviewers (TH and BH) who then collectively agreed on the initial list of clinical concepts. Clinical concepts, frequency of occurrence, and qualitative comments or quotes were noted for each of the interviews. These notes were reviewed by a third reviewer (ZG) and then discussed again with all reviewers to determine if the concepts should be included in the survey. The flow of information from each interviewer was vital to ensure that clinical concepts in analysis were unbiased and well-founded.

In Figure 1, below, a graphical summary of the interview review process has been provided to show the flow of conceptual ideation.

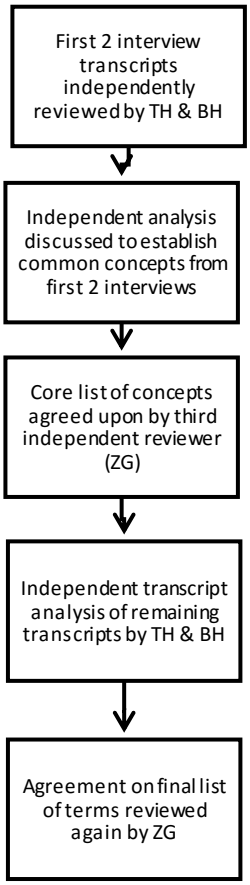

Figure 1: Interview Content Review Process: Flowchart of thematic analysis process between the 3 coordinating researchers: TH, BH, and ZG.

Survey Development and Deployment

Following the interview process, we distributed a survey to pediatric neurologists throughout the United States and Canada via a pediatric neurology email listserv. The survey asked respondents to rank the clinical concepts according to level of importance in treating a population of pediatric epilepsy patients. The survey

allowed subjects to arrange concepts in their order of preference. The initial order of the concepts in the survey were randomized for each subject. The survey also included an item to assess the degree of difficulty of access for each clinical concept within the electronic health record. This survey was approved for distribution by the Weill Cornell Medicine Institutional Review Board.

Prototyping Visualizations

We developed prototype dashboard visualizations using the Tableau Software package (http://www.tableau.com). We considered existing research in the field to inform the decision making process for prioritizing visualizations. Aesthetic principles and other visualization decisions were influenced by existing research in color theory, accessibility standards, and established guidelines for accurately representing information. (21,22) The rapid prototyping capabilities of Tableau allowed us to experiment with visualizations for different clinical topics as they emerged in interviews. Overall organization, order of presentation, and size of visualization, were based on the agreed upon importance of each clinical concept and the assessment of extraction difficulty.(23,24) To test various visualizations, representative patient data was used to simulate clinical use.

We developed visualizations using the Tableau Software package (http://www.tableau.com). We used the R programming environment for statistical analyses (http://www.R-project.org/). For the survey portion of this project, we used the web-based SurveyMonkey survey tool (http://www.surveymonkey.com) and performed additional analysis of survey data in R.

RESULTS

Interviews: Subjects

We reached the point of thematic saturation at the 11th interview. We continued with 3 more interviews for confirmation. A final sample of 14 participants was used in analysis. Through thematic analysis and the descriptive list generation process, we categorized responses into 9 categories with 26 subcategories. These appear in Table 1, with representative quotes from the interviews.

Table 1: Clinical Categories and Representative Quotes

Clinical Category	Representative Quotes
Insurance Characteristics	
Insurance Status/Type	"We have some private patients that go to ED, but it's typically our Medicaid population, ..."
Medication Data	
List of Medications	"…knowing what meds are patients are currently on, and have been on"
Failed Medication Trials (i.e., medications that were ineffective in the past)	"You typically have your first line med, then if that doesn't work you move to the next."
Medication Details (i.e., dose, route, dates of prescriptions, etc.)	"I guess the thing that comes up for us is patients on certain medications that are controlled substances and need to be filled on their medication more frequently, so knowing if the patient is on a certain medication would also be helpful if we need to follow up more closely."
Details of Dietary Therapy (i.e., Ketogenic Diet)	"Knowing if the kid is sticking to the ketogenic diet is very important."
Details of Device Settings (i.e., VNS)	"among other factors, the vagal nerve stimulator can be extremely effective in improving quality of life"
Side Effects of Medications	"If a child is in the ER, is it seizure related or is it a side-effect maybe? Some of these doses can be difficult to zero in on."
Comorbidities	
Psychiatric Comorbidities	"Does the child exhibit any other psychosocial or developmental issues that complicate treatment? Very important."
	" Sometimes they're bullied at school, sometimes they're depressed about they can't do certain things, restrictions. They're anxious. "
Neurologic Comorbidities	"MS and other neuro- disorders can make understanding future risk more difficult."
Medical Comorbidities	"Presence of a feeding tube, or difficulty breathing, these things affect how likely the kid is to have troubles."
Community Factors	
Reports from School System (i.e., Individualized Education Plan)	"Do patients get any special designation at the school since the diagnosis or starting the medicine and do they have ADHD?"

Table 1: (Continued)

Access / Use of Community Resources (i.e., support groups, advocacy organizations, etc.)	"I know that if my patient had the right resources, they will not go to the emergency room, …"
Stability of Housing	"Some of the families are in shelters and just use the emergency room as a source of healthcare for the children."
Barriers to Access	
Home Address	"So patients can live, like, two, three hours away with no – not much subspecialty access. "
Barriers to Access to Hospital Resources (i.e., problems with transportation, difficulty calling the clinic, etc.)	"There are patients who would stay home, because they live far from the emergency department and winters are bad in this region, rather than hoping on a bus to get to the hospital or getting a cab because they're really close and sort of thing. "
Previous Visits	
Epilepsy-related ED Visits	"How many emergency room visits did they do between the time they saw us first and second time and why were they there?"
Previous Visits, any setting, within your health system	"Even if the child visits an in-network ED, that information doesn't necessarily make it back to the outpatient clinic."
Previous Visits, any setting, outside your health system	"Parents, specifically in our area: [specific city], tend to be more likely to seek a second, third, fourth, etc. opinion. Rarely is this documented for clinical use. Doctor shopping definitely doesn't help us."
Appointment No-Show Rate (i.e., a summary of the number of missed appointments)	"Patients that tend to no-show for the appointments. Like usually if we get very difficult patients initially and when they tend to miss a lot of appointments especially in the beginning -- those tend to be the ones that go to the ER a lot. "
Family Communication Barriers / Facilitators	
Parents' Education Level	"Their education level may not be optimal. They may not understand. "
Parents' Socioeconomic Status	"Oftentimes they're families with less resources or their demand or need for services aren't matched by their resources. "

Table 1: (Continued)

Parents' Health Literacy	"Make sure that the parents have diazepam, they have emergency medication plans, know when to use it and when to bring to the ER. "
Parents' Adherence to Treatment Plan	"Is the mother really giving the medicine and they've been in the ER a couple of times and they're falling or if they have frequent seizures, if they're prepared to have a rectal Valium or things like that."
Parents' Mental Health	"parental anxiety or parental mental health disorders make up another big red flag. "
Description of a Seizure Action Plan	"Those patients that have that plan, less likely to use resources, as opposed to if you don't have an emergency plan or an epi plan, they will just panic and come in to the ED."
Number of Siblings / Birth Order	"…, are there other siblings there and do they have any other responsibilities that they have to do or if other parents are they invested in the care of the children or is it cumbersome? "
Parents' Primary Language	"We have the ability of interpreters over the phone, which is the primary way that we deal with it, but the quality of the phone interpreters is not always great, and it can be difficult sometimes if you are on the phone with the interpreter and they have a question later, you have to wait to get back on the phone. "
Testing Results	
Genetic Testing Results	"Have they been seen by genetics, who are looking for those mutations…?"
Routine Lab Data (CBC, AED levels, etc.)	" The idea that predicting ED use from anything gravitates toward variables that change, like lab values over time or number of tests performed."
Number of MRIs or CTs	"Just knowing how many head imaging procedures MRIs have been done was one thing we looked at for showing future risk. "
Number of EEGs	"Has that same patient been in for an overnight EEG, and how many routines have been looked at? "

Table 1: (Continued)

EEG Findings	"Just simply being able to see abnormal, or normal EEG findings in a simple way would really help identify those risky patients."
MRI Findings	"Not only is number of MRI important, but if the findings were abnormal or normal as well."
Surgical Work-Up Summary	" I'm sometimes thinking in a refractory patient where, 'What is – is this a surgical candidate? What is the next thing I can do?' "
Epilepsy Characteristics	
Seizure Types	"… -- obviously, intractable epilepsy patients need more attention;"
Epilepsy Syndrome	"So they're defined by diagnosis, if there was a known diagnosis, so specific epilepsy syndrome. "
Seizure Frequency	"It's hard to accurately gauge how often seizures are occurring based on the parent's count, but that is important in judging those patients"
Epilepsy Etiology	"The makeup of the seizure disorder and the type of side-effects of medications and symptoms of the disorder are important in understanding how the family needs access to resources."
Seizure Severity	"Are they going into status more commonly or something less intense? Those status patients may have to be in the ED more often for other complications."

Insurance Characteristics

Many participants mentioned insurance status as a distinct indicator for future ED utilization. The primary elements from this category were insurance status, (i.e. patients were or were not insured), and insurance type, (i.e. patients with public insurance vs private insurance). Physician opinion gravitated toward the idea that patients with public insurance would be at higher risk for future ED visits due to a number of factors related to insurance type.

Medication Data

Medications proved to be relevant to ED utilization in terms of the number of medications and the type of medication. The number of medications relates well with severity of epilepsy and also introduces risk for medication errors. When asked which subset of children with epilepsy take the most mental effort to manage, one participant responded: *"Kids who are being managed on multiple medications."* Visualizing the type of medication would potentially be usable in situations where children are prescribed DEA scheduled drugs that require more rigorously defined prescribing guidelines. For example, one participant responded *"I guess the thing that comes up for us is patients on certain medications that are controlled substances and need to be filled on their medication more frequently, so knowing if the patient is on a certain medication would also be helpful if we need to follow up more closely."*

Comorbidities

Physician opinion on co-morbidities in complicated epilepsy cases varied. In the interviews, participants mentioned musculoskeletal, developmental, psychosocial and

behavior comorbidities. These repeated comorbidities were grouped into psychiatric, neurologic, and medical comorbidities based on feedback from the interviewees.

Community Factors

Community factors included school support, access/use of community resources, and stability of housing. For the school support subcategory, several participants mentioned that identifying different types of epilepsy sometimes happens in the classroom. This subcategory also covered the topics of disability student support services, including Individualized Education Plans and other programs. Use of community resources was brought up in interviews as a way of assessing how families make use of condition-specific support groups and other advocacy organizations.

Barriers to Access

This category was used to aggregate external factors not directly related to parental behavior or community. The most commonly referenced barrier was geographic location. Physician opinion on the importance of the geographic location in predicting future ED utilization varied according to the interviewee's location. For example, a pediatric neurologist in a regional center that managed patients from 5 states, said that *"geographic location is the most significant factor"* in considering how likely a patient is to visit the ED in the future. In comparison, interviewee's based in Manhattan said geographic location only really influences which ED they choose to go to, not if they go or not. The "Barriers to Access" sub-category also covers phone access and language barriers in contacting outpatient clinics. Participants responded that different cultures may rely more on internal "community" doctors and health providers than seeking clinic-provided care.

Previous Visits

In the 'Previous Visits'' category, compliance with appointments and proclivity to "doctor-shop" were documented as the most common clinical concepts relevant to preventing future ED use. There is slight overlap here with 'Parent Characteristics' often the conversation led from one to the other or vice-versa. The most commonly reported item out of all clinical concepts in the interview stage was the "number of previous ED visits." This factor is one of the few confirmed predictors of future ED visits.

Family Communication Barriers/Facilitators

This category section spans many subcategories. In relation to ED use, the most significant concept for physicians to know was socioeconomic status. Interviewee's reported that older parents, and parents with more children seemed less likely to overuse the ED for epilepsy-related events. This idea was also phrased in interviews as parental anxiety, or parental beliefs. Similarly, the presence/use of an emergency seizure plan by parents was a common thematic element.

Testing Results

Responses that covered any sort of lab procedure or imaging test were grouped into this category. One opinion that surfaced multiple times was that the number of MRIs or CTs would directly predict how many times the child may visit the emergency department. One participant stated that the ability to easily check if an EEG was "Normal/Abnormal" as her central suggestion for improvement for current EMRs.

Epilepsy Characteristics

The most referenced concepts in this study in the interview stage were epilepsy syndrome, seizure severity and seizure type. In the interviews, responses in this category would be the first mentioned in reference to predicting future ED visits. One participant summarized the idea as, *"Well, the epilepsy severity, I think, is your biggest marker; those kids are not well controlled."*

Other Concepts

The topic of individual versus population level care was mentioned in several interviews. Because this is a physician characteristic, rather than a patient characteristics, these findings were not included as a clinical concept. One pediatric neurologist highlighted this conceptual difficulty: *"I guess I don't think of things as much – I think there's so much individual variability that I don't think of things on a population basis, I guess, maybe as much as some other people do."*

Survey: Participant Demographics

Our survey received 16 responses. All survey respondents answered that they provided care to children with epilepsy. Of the 16 responses, 13 participants reported working as pediatric epilepsy specialist, 2 reported working as a pediatric neurologist, and 1 reported working as a nurse practitioner. There were no students, residents, or fellows in our survey response data. There were responses recorded from 11 states, as seen in Table 2 below.

Table 2: Physician Demographic Data from Survey Collections

Physician Demographics		
Provide care to children with epilepsy?		
Yes	100.0%	16
No	0.0%	0
Role?		
Pediatric neurologist	12.5%	2
Pediatric epilepsy specialist	81.3%	13
Nurse Practitioner / Physician Assistant	6.3%	1
Student, resident or fellow?		
Yes	0.0%	0
No	100.0%	16
Geographic area?		
Alabama	6.3%	1
Colorado	12.5%	2
District of Columbia (DC)	6.3%	1
Maryland	6.3%	1
Michigan	6.3%	1
New York	18.8%	3
Ohio	12.5%	2
Oregon	6.3%	1
Pennsylvania	12.5%	2
Texas	6.3%	1
Washington	6.3%	1

Survey: Concept Ranking

Participants in the survey ranked epilepsy characteristics as the most important clinical concept in managing a population of children with epilepsy. Of the responses, epilepsy characteristics was ranked first by 13 of 16 participants, or ~81%. The second and third most important clinical categories were medication data and testing results respectively. These categories were distinct in ranking while the remaining 6 categories were more varied in where they were placed further down in respondents lists. Table 3, below, provides additional information concerning the ranking average, ranking medians, percent ranked 1st, and response count.

Table 3: Clinical Concept Ranking from Survey Respondents

Clinical Concept	Ranking Average	Ranking Median	Percent Ranked 1st	Responses
Epilepsy Characteristics (Syndrome, Etiology, Severity, Seizure Frequency, Seizure Types)	1.69	1.00	78.26%	16
Medications (Type of Medication, Number of Medications, Dietary Therapies, Devices)	2.81	3.00	0%	16
Testing Results (Genetics, Routine Labs, EEG, MRI, Surgical Evaluation)	3.69	3.00	8.70%	16
Comorbidities (Psychiatric, Neurologic, Medical)	4.88	4.00	0%	16
Previous Healthcare Visits (ED, Inpatient, Outpatient, No-show rate)	4.88	4.00	4.3%	16
Parent Characteristics (Education Level, Socioeconomic Status, Health Literacy, Adherence, Mental Health)	6.00	6.00	0%	16
Barriers to Access (Geographic Location, Language Barriers, Hospital Access)	6.50	6.00	9.09%	16
Insurance Status/Type	6.94	7.00	0%	16
Community Factors (School Support, Social Support, Stable Housing)	7.63	8.00	0%	16

Survey: Extraction Difficulty

In the response for the difficulty of extraction from existing electronic medical record data, participants assigned a value between 1 and 4. The easiest data points to extract included: insurance status/type, list of medications, neurologic and medical comorbidities, home address, previous visits (within respondent's health system), and seizure types. The most difficult data points to extract included: access/use of community resources, stability of housing, parents' mental health, parents' health literacy, and parents' education level. Table 4, below, shows the extraction difficulty rankings, as sorted from most difficult to least difficult in each clinical category.

Table 4: Data Extraction Difficulty from Survey Including Rating Average, Rating Median, and Difficulty (1 (+): Easiest to 4 (++++): Impossible)

Clinical Category	Rating Average	Rating Median	Difficulty	Response Count
Insurance Characteristics				
Insurance Status/Type	1.33	1.00	+	15
Medication Data				
Failed Medication Trials (i.e., medications that were ineffective in the past)	2.19	2.00	++	16
Side Effects of Medications	2.13	2.00	++	16
Details of Device Settings (i.e., VNS)	1.88	2.00	++	16
Details of Dietary Therapy (i.e., Ketogenic Diet)	1.75	2.00	++	16
Medication Details (i.e., dose, route, dates of prescriptions, etc.)	1.13	1.00	+	16
List of Medications	1.06	1.00	+	16
Comorbidities				
Psychiatric Comorbidities	2.13	2.00	++	16
Neurologic Comorbidities	1.44	1.00	+	16
Medical Comorbidities	1.44	1.00	+	16
Community Factors				
Access / Use of Community Resources (i.e., support groups, advocacy organizations, etc.)	3.88	4.00	++++	16
Stability of Housing	3.88	4.00	++++	16
Reports from School System (i.e., Individualized Education Plan)	3.00	3.00	+++	16
Barriers to Access				
Barriers to Access to Hospital Resources (i.e., problems with transportation, difficulty calling the clinic, etc.)	3.19	3.00	+++	16
Home Address	1.06	1.00	+	16
Previous Visits				
Previous Visits, any setting, outside your health system	2.63	3.00	+++	16
Appointment No-Show Rate (i.e., a summary of the number of missed appointments)	2.00	2.00	++	16
Epilepsy-related ED Visits	1.88	2.00	++	16
Previous Visits, any setting, within your health system	1.13	1.00	+	16
Family Communication Barriers / Facilitators				
Parents' Mental Health	3.87	4.00	++++	15
Parents' Health Literacy	3.63	4.00	++++	16
Parents' Education Level	3.25	4.00	++++	16

Table 4: (Continued)

Parents' Adherence to Treatment Plan	3.13	3.00	+++	16
Parents' Socioeconomic Status	3.06	3.00	+++	16
Number of Siblings / Birth Order	2.44	2.00	++	16
Parents' Primary Language	2.00	2.00	++	16
Description of a Seizure Action Plan	1.75	2.00	++	16
Testing Results				
Surgical Work-Up Summary	2.06	2.00	++	16
Genetic Testing Results	1.94	2.00	++	16
Number of MRIs or CTs	1.56	2.00	++	16
Number of EEGs	1.56	2.00	++	16
EEG Findings	1.25	1.00	+	16
Routine Lab Data (CBC, AED levels, etc.)	1.25	1.00	+	16
MRI Findings	1.20	1.00	+	15
Epilepsy Characteristics				
Epilepsy Etiology	1.69	2.00	++	16
Seizure Frequency	1.63	2.00	++	16
Epilepsy Syndrome	1.56	2.00	++	16
Seizure Severity	1.56	2.00	++	16
Seizure Types	1.38	1.00	+	16

Prototyping Dashboard

The design of the prototype dashboard was influenced according to existing standards for visualizations. Initial designs were created using narrowed visual elements to include the most common visualizations: pie charts, bar charts, scatterplots, function plots, maps, mosaics, and radar charts. The initial development of the prototype dashboard was conducted in parallel with the interview stage of the research, allowing for an iterative process of configuration. As seen in Figure 2 below, the first prototype reflected participant interest in geographic location, insurance type, and the number of previous ED visits.

Figure 2: This figure shows an early concept named "Prototype 1." Here, the primary emphasis is on providing visualization of the Geographic Location, Insurance Type, Prev. ED Visits clinical categories.

The progression from Prototype 1 to Prototype 2 reflects the frequency of medication type, medication counts, and overall healthcare encounters. Although geographic location was dropped from this version, Insurance type, medication name, and care types were included as actionable filters that affected the visualizations displayed. As seen in Figure 3, below, this version also included a visualization of the number of sample patients who visited the ED in 2013 and revisited the ED in 2014.

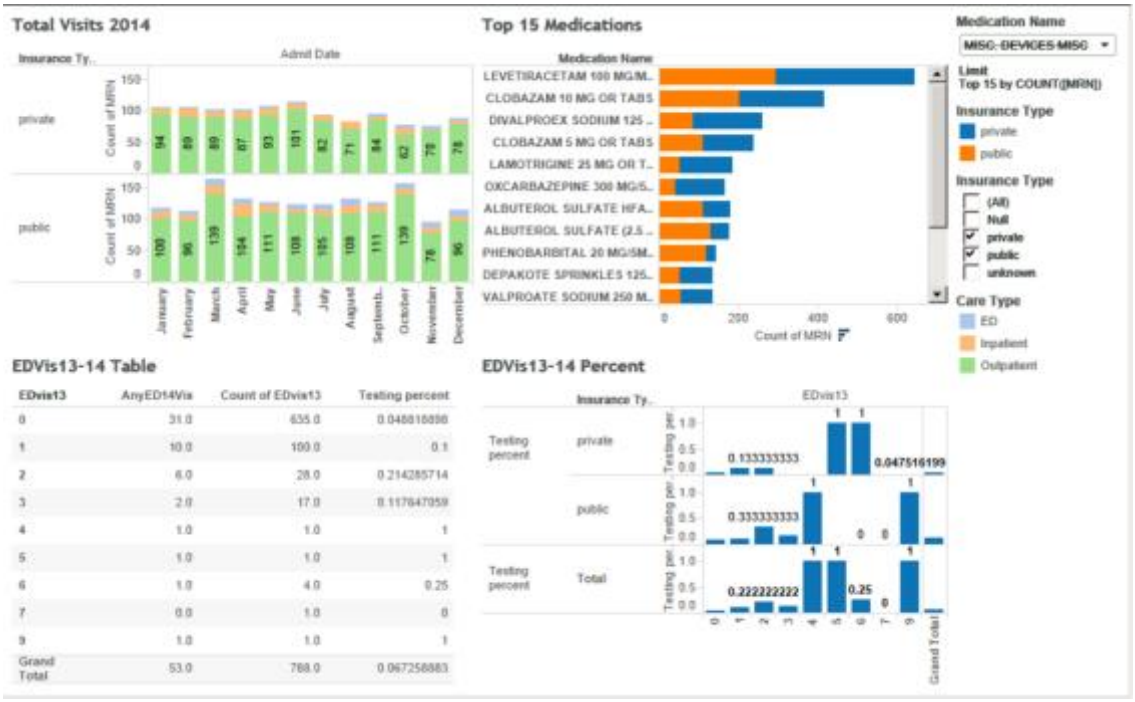

Figure 3: This figure shows another early concept named "Prototype 2." Here, the primary emphasis is on providing visualization of the Total Visits for one year, (2014) as detailed by visit-type. The Top 15 medications according to insurance type appear in the mid-right corner, while the "Actionable Filters" interface is present in the far right. The bottom two tables and visualizations show likelihood of future visits based on insurance status and previous visits.

Prototype 3 was built as a mock-up to reflect the changes in the conclusion of the interview process. This mock-up allowed for quick manipulation of different "modules" associated with clinical concepts gained in the qualitative portion of the research. In this example, the modules reflected introduce increased flexibility in visualization customization and introduce the "Top 10" lists to identify patients who may need increased attention in the ambulatory setting. Figure 4, below, provides an illustration of a mock prototype based on the module conceptualization of the clinical dashboard.

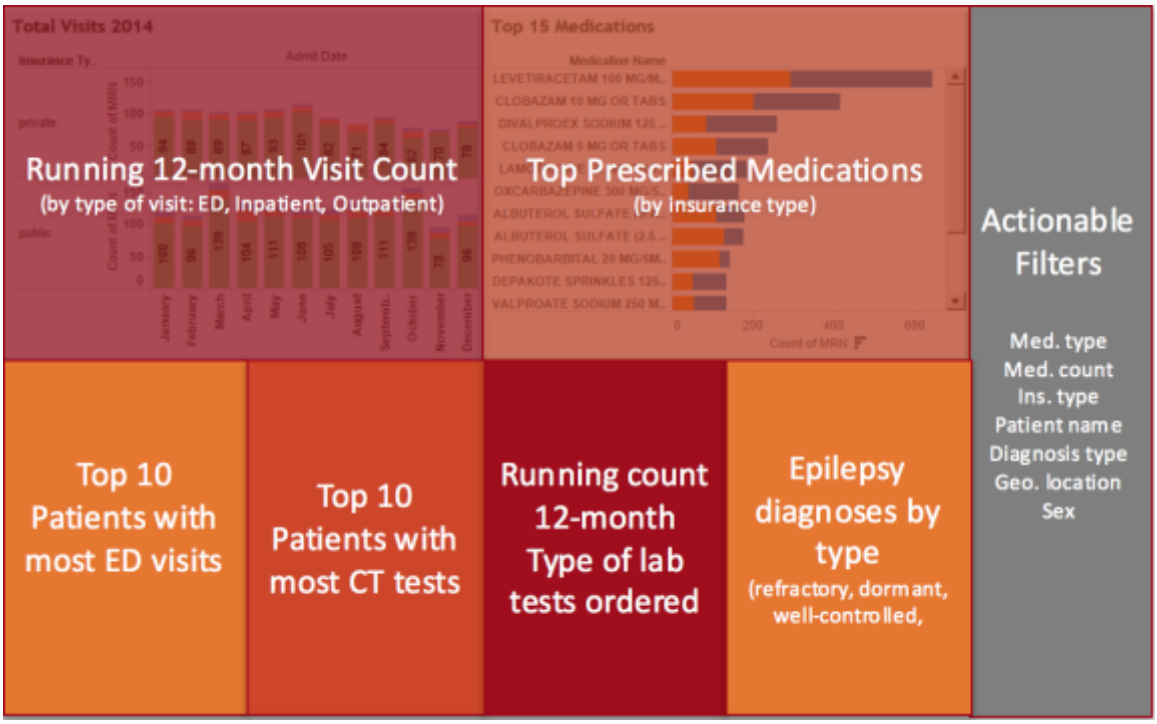

Figure 4: This shows an estimated mock-up for how "Prototype 3" would be presented as a potential use-case in different settings. The "hot-switchable" modules shows areas that can be interchanged for what the neurologist/nurse/social-worker/care manager would most like to manage.

DISCUSSION

Summary of Findings

Physician agreement on epilepsy characteristics, medication data, and comorbidities as the top three clinically relevant concept indicates the importance of these clinical concepts in providing appropriate care to pediatric epilepsy patients. Using existing data sources to visually compile relevant information to identify potential future ED visits can improve the care process for children with epilepsy. Identifying children who may be at higher risk for future emergency department visits can reduce overall healthcare utilization and provide a better quality of life for the patient and patient's family. Quick access to relevant information can influence decision making in the outpatient center and help physicians and support staff identify patients who are outliers in clinical data.

Significance of Specific Finds

Many elements that are important in assessing future emergency department visits are not available in the electronic medical record, or are difficult for physicians to access in a clinical encounter. Of the concepts identified by the sample of pediatric neurologists, the most useful may be hidden in social worker case notes, or stored in an incompatible data format. An automatically populated list of parent characteristics as identified in the interview process could help caregivers identify children who may be at risk for future ED visits before those ED visits occur. This research helps inform future projects that may aim to generate predictive models or algorithmic identification of pediatric patients at risk for future epilepsy-related ED visits.

Limitations

The limitations in a prototype dashboard relate to the availability of data about the concepts explored. For instance, although parent education level may exist somewhere in a child's medical record, it is not easy to assess/extract at a population level. Some elements indicated to be important in managing a population of children with epilepsy are not readily available in EHR data but can serve to influence future research.

Conclusions and Future Work

Within each clinical category, there are topics that can potentially be addressed with future research. There may be a link between the number of patients seen per week and the physicians' proclivity to think at a population-based overview. Education and health literacy were also commonly mentioned. The relationship between these two variables and socioeconomic status have been discussed in other research. (25, 26)

Future research in development of a clinical dashboard will include usability analysis techniques to provide quantifiable verification of the most useful visualization methods for the clinical dashboard.

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